

In The
Supreme Court of the United States
October Term, 1969

**LOUIS W. SULLIVAN, SECRETARY OF HEALTH
AND HUMAN SERVICES,**

Petitioner,

v.

BREAN SMILEY, et al.,

Respondents.

On Writ of Certiorari to the
United States Court of Appeals
for the Third Circuit

**AMERICAN MEDICAL ASSOCIATION,
AMERICAN ACADEMY OF PEDIATRICS,
NATIONAL ORGANIZATION FOR
RARE DISORDERS, INC. AND
THE SPINA BIFIDA ASSOCIATION OF AMERICA
AS AMICI CURIAE IN SUPPORT OF RESPONDENTS**

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QUESTION PRESENTED

Whether the regulatory scheme utilized by the Secretary of Health and Human Services for determining when a child is eligible for disability benefits under 42 U.S.C. § 1382c(a) is consistent with Congress's intent and sound medical practice.

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INTEREST OF *AMICI CURIAE*

Amicus American Medical Association ("AMA") is a private, voluntary, non-profit organization of physicians. The AMA was founded in 1846 to promote the science and art of medicine and to improve the public health. Its 280,000 members—over half of all physicians currently licensed to practice medicine—provide care in all fields of medical specialization, including pediatrics.

Amicus American Academy of Pediatrics ("AAP") was founded in 1930 in order to create an independent

forum for the special health and development needs of children. It is a nonprofit association of approximately 38,000 physicians in the United States, Canada and Latin America certified in the specialized care of infants, children and adolescents. The AAP's principal purpose is to ensure the attainment by all children of their full potential for physical, emotional and social health.

Amicus National Organization for Rare Disorders, Inc. ("NORD") is a non-profit voluntary health agency of medical researchers, voluntary agencies and individuals dedicated to the identification, control and improved treatment of rare orphan diseases, those diseases which individually afflict fewer than 200,000 Americans. There are more than 5,000 orphan diseases, which touch the lives of an estimated 20 million people in this country. A disproportionate number of those afflicted by rare diseases are children.

Amicus Spina Bifida Association of America ("SBAA") is a nonprofit charitable membership organization that provides support for children and adults with spina bifida and their families. SBAA has 80 chapters across the country who provide volunteer support and advocacy for families and medical and other professionals who live with and care for people with spina bifida. SBAA supports research efforts into the cause and treatment of spina bifida, public awareness, development of educational materials and advocates improved medical care and social services to those afflicted with this most common disabling birth defect.

Amici's interest in this case derives from a shared concern for the welfare of patients—SBAA and NORD for the particular populations they serve, and AMA and AAP for overall patient care. *Amici's* extensive experience in identifying and treating children who are afflicted by disabling physical and mental impairments permits them to offer the Court unique insights into the assumptions behind and operation of the regulatory system for compen-

sating the disabled implemented by the Secretary of Health and Human Services.

In particular, *amici* are profoundly troubled by the approach followed by the Secretary because it systematically fails to provide assistance to those most disadvantaged of all in our society, viz, poor, disabled children. The Secretary's present interpretation of Title XVI is especially disturbing to *amici* because a child's eligibility for Medicaid assistance, a crucial source of funds for essential medical care for low income individuals, is often tied directly to a Title XVI disability determination. See generally, Fox & Greaney, *A Preliminary Assessment of Disabled Children's Access to Supplemental Security Income and Medicaid Benefits* 4-5, 42 (Washington, D.C. Dec. 1988). Thus, when a child is denied benefits under Title XVI, funds for vital medical care are significantly delayed and may be completely denied, which can only exacerbate the developmental problems these children will experience. Accordingly, *amici* wish to present their views concerning why the Secretary's approach is not only inconsistent with good medical practice but also manifestly inconsistent with Congress's intent when it included children within the coverage of Title XVI.¹

MEDICAL BACKGROUND

A. The Importance Of Development And Functional Capacity In Pediatric Medicine.

Children's health needs differ from those of adults in part because of the different ways children think, experience emotion or pain, respond to stress, metabolize drugs and manifest disease. A primary concern of pediatric medicine is to prevent potentially debilitating illness or injury from arresting a child's development of the characteristics and skills essential to adulthood. Thus, while

¹ Pursuant to Rule 36 of the Rules of this Court, the parties have consented to the filing of this brief. Their letters of consent have been filed with the Clerk of Court.

all physicians are concerned with the health of their patients, pediatricians and other physicians who treat children share a special, additional obligation: to help their patients *develop* so that they may attain "their full potential for physical, mental, emotional and social health."²

The developmental component of the practice of pediatrics has implications that are very important to respondents in this case. Good pediatric medical practice requires a physician to pay close attention to the effects of illness or injury on developing functional skills—cognitive, emotional and social, as well as physical—which are essential to the child's successful growth into self-sufficient adulthood. The physician's task includes not only treating the child's immediate illness or injury, but also identifying the steps that are essential to permit the child's overall development to proceed as normally as possible. See generally Guralnick & Bennett, A Framework for Early Intervention, in *The Effectiveness of Early Intervention for At-Risk and Handicapped Children* 14, 24 (Guralnick & Bennett eds. 1987) ("Effectiveness of Early Intervention").

The pediatric literature is replete with examples of the importance to pediatric medicine of functional assessments. In the area of pediatric research, assessments of children's cognitive, emotional, social and physical condition are routinely analyzed through research into children's play. E.g., Fein, *Pretend Play In Children: An Integrative Review*, 52 *Child Development* 1095,

² The adult's internist "specializes in the diagnosis and medical, as opposed to surgical and obstetrical, treatment of diseases of adults." *Dorland's Illustrated Medical Dictionary* 673 (26th ed. 1985). The child's pediatrician practices "that branch of medicine which treats diseases of the child and [the child's] *development* and care of the diseases of children and their treatment." *Id.* at 979 (emphasis supplied). As stated in the Preamble to the Constitution of *Amicus American Academy of Pediatrics*, the Academy's "fundamental goal" is to assure "that all children and youth have the opportunity to grow up safe and strong, with faith in the future and in themselves."

1109 (1981); Ghiaci & Richardson, *The Effects of Dramatic Play Upon Cognitive Structure and Development*, 136 *J. Genetic Psychology* 77 (1980). In addition, pediatricians routinely include among the goals of treatment of any childhood disease, as well as management of its symptoms, "help[ing] the child perform ordinary daily age-appropriate activities." Schwartz, *Children with Chronic Asthma: Care by the Generalist and the Specialist*, 31 *Pediatric Clinics of North America* 87, 89 (1984).

The view that proper study or treatment of pediatric illness and injury must include an assessment of the child's functional capacity to perform age-appropriate activities is well accepted in the medical community.³ This view takes on special importance when the physician is called upon to assess a child's condition according to the severity of his or her medical condition. The biological severity of an illness is an abstraction, measured only by proxies, the most familiar of which are physiological severity, functional severity and burden of illness. Stein, *et al.*, *Severity of Illness: Concepts and Measurements*, II *The Lancet* 1506, 1507 (December 26, 1987). Physiological severity may be greatly altered by therapy and social circumstances. For instance, emotional stress can exacerbate the physiological severity of several fairly common childhood diseases, including asthma, inflammatory bowel disease, juvenile rheumatoid arthritis and diabetes. *Id.* Partly for this reason, disease-specific measures of physiological severity are often questionable, and

³ Many pediatric commentators have pointed out the inadequacy of any medical diagnosis that does not include an assessment of the child's functional ability to perform age-appropriate tasks. For example, a major pediatric text concludes a chapter on diagnosis with the observation that where information is missing about the child's performance in one developmental area, such as cognitive skill, the pediatrician simply must refrain from making a final diagnosis in another area, such as the origins of a behavioral problem with school adjustment. See Levine, *et al.*, *Developmental-Behavioral Pediatrics* 1039 (1983).

there is general agreement that such measures are of little use in children with, *inter alia*, rare conditions or multiple disorders. *Id.* Consequently, there is no way meaningfully to separate a clinician's functional assessment from medical diagnosis and treatment of many childhood disabilities and any attempt to do so distorts proper medical practice.

B. Good Pediatric Practice Requires Individualized Medical Assessments.

Pediatricians widely agree, for several reasons, that effective diagnosis and treatment of childhood disability, or of potential disability in the case of the child "at risk," requires the exercise of individualized medical judgment. *E.g.*, Healy, *et al.*, *Early Services for Children With Special Needs: Transactions for Family Support* (2d ed. 1989). First, where chronic illness in adults "consists mainly of a relatively large number of fairly common illnesses (such as hypertension, diabetes and osteoarthritis) and a few rare diseases, chronic illness in childhood is characterized by very few disorders that are common and by many that are quite rare." Pless & Perrin, *Issues Common to a Variety of Illnesses*, in *Issues in the Care of Children with Chronic Illness* 41, 43 (Hobbs & Perrin eds. 1985). Because there are so many rare diseases of childhood, it is unlikely that any individual physician, who will see only a few, if any, such cases in a lifetime of practice, will become expert in the diagnosis or treatment of many rare childhood diseases. The nature of childhood disease thus emphasizes the need for a careful and comprehensive assessment of each individual child. See, *e.g.*, Schwartz, *Children with Chronic Asthma: Care by the Generalist and the Specialist*, 31 *Pediatric Clinics of North America* 87 (1984).

Second, an individualized assessment of disability is important because individual variables have a significant

impact on the child's overall condition and development.⁴ An individualized assessment is essential in order to make adequate diagnoses and treatment plans. Finally, as discussed above, pediatric medicine serves a developmental as well as a treatment-of-illness purpose. Adequate assessment of a child's condition at any given time necessarily includes a broad view of his or her functional abilities across a range of developmental dimensions. To draw together the disparate evidence needed to make a competent and comprehensive diagnosis and treatment plan, the physician must give careful attention to each child's individual circumstances and functional abilities.

C. The Importance Of Early Intervention In Treating Disabling Impairments Among Children.

The developmental goal of pediatric medicine has another implication for good medical practice: medical intervention should occur before illness or injury becomes sufficiently severe to affect the child's functioning in other developmental dimensions. It is well-established, for example, that children with documented handicaps have more difficulty establishing secure attachments with their parents during infancy,⁵ and developing peer rela-

⁴ For example, in the area of memory, research has shown that it is the child's individual cognitive development, not his or her chronological age, that determines ability. Walker *et al.*, *Cross-Cultural Research with Children and Families*, in *Handbook of Clinical Child Psychology* 74 (Walker & Roberts eds. 1983). Similarly, research has shown that individual differences in temperament can affect a child's development. *Id.* at 75.

⁵ Guralnick & Bennett, *A Framework for Early Intervention, in Effectiveness of Early Intervention* at 14. See also Healy, *et al.*, *Early Services for Children with Special Needs* 21-25 (2d ed. 1989). This difficulty is thought to be caused by the handicapped child's inability to signal and display affective responses that engage the parent. Guralnick & Bennett, *A Framework for Early Intervention, in Effectiveness of Early Intervention* at 15. This pattern has been documented in children with several different kinds of disabilities: hearing impairments, Down syndrome, other developmental delays and cerebral palsy. *Id.* See also Perrin, *et al.*,

tionships and general communicative skills. Guralnick & Bennett, *A Framework for Early Intervention*, in *Effectiveness of Early Intervention* at 16-17. These deficiencies can have far-reaching effects. For example, without early intervention to prevent or minimize these secondary deficits that result from the child's primary handicap, the child may be tracked into an educational program more restrictive than his or her abilities would allow if properly treated early. As a result, the child may never reach full adult potential, and some children who could have become self-sufficient adults will not develop that capacity.⁶ It is therefore vital that children with significant medical impairments receive early professional care and any regulatory approach that decreases the likelihood that younger children will receive medical attention will have potentially devastating and long-term consequences for those children.

In sum, the developmental goal of pediatric medicine has important implications for the issues presented in this litigation. Good medical practice calls for treatment to be preceded by comprehensive, individualized assessments of the child's medical condition, including his or her ability to perform age-appropriate functions.

SUMMARY OF ARGUMENT

I.

Nearly 20 years ago, Congress established the Supplemental Security Income program to provide benefits to financially needy individuals who are aged, blind, or disabled. This Court has previously recognized that Congress

Parental Perceptions of Health Status and Psychologic Adjustment of Children with Asthma, 83 *Pediatrics* 26 (1989).

⁶ The available evidence is that early intervention works. For example, the measured decline in Down syndrome children's intelligence as they grow older can be prevented and to some extent reversed with the adoption of appropriate early intervention strategies. Guralnick & Bricker, *Cognitive and General Developmental Delays*, in *Effectiveness of Early Intervention* at 135-67.

intended that all disability determinations under the SSI program would be based on an individualized assessment. *Heckler v. Campbell*, 461 U.S. 458, 467 (1983). And, in fact, the Secretary has established a regulatory scheme for *adults* that provides for individualized disability determinations based on the functional impact of physical and mental impairments.

From the inception of this program, Congress explicitly sought to extend the program's benefits to disabled children, because, in Congress's words, they are "among the most disadvantaged of all Americans and . . . are deserving of special assistance." S. Rep. No. 1230, 92d Cong., 2d Sess., *reprinted in* 1972 U.S. Code Cong. & Admin. News 5132, 5133. Congress further intended that children, like adults, would be considered for benefits based on an individualized consideration of the functional impact of their physical and mental impairments. Nevertheless, the Secretary has in recent years adopted restrictive regulations that prevent such individualized determinations for children and thus deny significant numbers of disabled children from low income households the benefits that Congress intended them to receive.

The Secretary's present interpretation of the statute as it applies to children is plainly at odds with the language of the statute as well as with the contemporaneous and subsequent legislative history. Moreover, the Secretary's present restrictive interpretation is contrary to his own interpretation as disseminated within the agency, and communicated to Congress, in the program's early years. At that time, the Secretary fully and correctly acknowledged the importance of considering the impact of a medically determinable impairment on the individual child's growth, development and maturation. See Social Security Administration Disability Insurance Letter No. III-11 (Sept. 7, 1973) (J.A. 90). It was *this* interpretation of the statute that Congress was aware of in 1976, *not* the Secretary's more recent listings-only ap-

proach, reflected most clearly in a policy statement some seven years later. Social Security Ruling 83-19 (1983) (J.A. 236). Thus, any acquiescence by Congress in 1976 reflected continued support for individualized disability determinations, including an individualized assessment of the functional impact of each child's physical or mental impairment.

II.

The deference in interpreting the statutes he administers that the Secretary is customarily accorded by this Court is not sufficient to justify his present regulatory scheme. The regulatory history of the program contradicts the Secretary's suggestion that his interpretation of the statute should be respected here because it is longstanding. Moreover, the individualized consideration of functional factors is quite feasible and, in fact, required under sound medical practice. As the Secretary himself has recognized, the listings necessarily exclude many disabling conditions. Because of the particular manifestation of disability in children, this inherent limitation has particularly damaging consequences that are not ameliorated by the Secretary's medical equivalence regulations. By prohibiting an individualized assessment of each child's medically determinable impairment and resulting functional limitations, the Secretary has established a regulatory system that is arbitrary and capricious.

ARGUMENT

I. THE SECRETARY'S REGULATORY SCHEME FOR DETERMINING WHEN CHILDREN ARE ELIGIBLE FOR DISABILITY BENEFITS UNDER THE SUPPLEMENTAL SECURITY INCOME PROGRAM IS INCONSISTENT WITH THE STATUTORY LANGUAGE AND WITH CONGRESS'S INTENT.

It is well established that agencies are accorded considerable latitude in construing the statutes that they administer. *Chevron, U.S.A. v. Natural Resources Defense Council*, 467 U.S. 837 (1984). Moreover, the Sec-

retary has been given reasonably broad authority to establish standards for applying certain sections of the Social Security Act, *Bowen v. Yuckert*, 482 U.S. 137, 145 (1987). However, the deference accorded to an agency's interpretation is not absolute: if the intent of Congress is clear, the agency and the courts must give effect to that congressional intent. *Chevron*, 467 U.S. at 842-43. And, even where Congress has not directly addressed the precise question, the agency's interpretation may be rejected where the court determines that the agency's interpretation is not reasonable. *Id.* at 843-44. In the present case, it is clear that the congressional scheme contemplates that the Secretary will conduct "individualized [disability] determinations . . . of each individual's condition." *Heckler v. Campbell*, 461 U.S. 458, 467 (1983).⁷ As we show below, the Secretary has implemented that approach for adults but not children.

A. The Statutory Language Requires The Secretary To Consider Individual Functional Impairment In Making Assessments Of Childhood Disability.

The Supplemental Security Income (SSI) program, enacted in 1972 as Title XVI of the Social Security Act, 42 U.S.C. § 1381 *et seq.* (1981 & Supp. IV 1986), generally provides benefits to financially needy individuals who are aged, blind or disabled. See *Schweiker v. Wilson* 450 U.S. 221, 223 (1981), quoting S. Rep. No. 1230, 92d Cong., 2d Sess. 4, 12 (1972).

The Social Security Act provides that an individual is eligible for disability benefits when:

he is unable to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected

⁷ Because the Title XVI provisions that are at issue in this case were patterned on the previously enacted Title II language found at 42 U.S.C. § 423, it is customary to refer to the cases that have interpreted Title II when construing the meaning of the identical Title XVI language. *Bowen v. City of New York*, 476 U.S. 467, 470 (1986).

to result in death or which has lasted or can be expected to last for a continuous period of not less than twelve months (or, in the case of a child under the age of 18, if he suffers from any medically determinable physical or mental impairment of comparable severity).

42 U.S.C. § 1382c(a)(3)(A). For a wage earner, the statute requires that the Secretary determine if the claimant is unable to "engage in any other kind of substantial gainful work which exists in the national economy . . ."

42 U.S.C. § 1382c(a)(3)(B). For a child, however, the statute does not specify the level of impairment, other than to say that it must be of "comparable severity."

42 U.S.C. § 1382c(a)(3)(A). For both adults and children, the statute provides that a physical or mental impairment is one which "results from anatomical, physiological, or psychological abnormalities which are demonstrable by medically acceptable clinical and laboratory diagnostic techniques." 42 U.S.C. § 1382c(a)(3)(C). At issue in this case is the appropriate meaning of the phrase "any medically determinable physical or mental impairment of comparable severity."

In interpreting the phrase "comparable severity," it is helpful initially to review the regulations enacted by the Secretary for adults. These regulations establish a five-step process designed to ensure each adult an individualized determination of disability. 20 C.F.R. § 416.920 (1986). In the first three steps, the Secretary evaluates whether the individual is engaging in any substantial gainful activity; if not, then the Secretary looks for the existence of a medically severe impairment; and if such an impairment is found to exist, whether that impairment is equivalent to one of a number of listed impairments that are extremely severe. 20 C.F.R. § 416.920(d); 20 C.F.R. pt. 404, subpt. P, App. 1 (1986) (commonly referred to as the Part A listings). If the impairment meets or equals a listed severe impairment, the claimant is "conclusively presumed to be disabled." *Bowen v. Yuckert*, 482 U.S. at 141. The listings thereby serve to

identify quickly and uniformly claimants whose impairments are so severe that an individualized assessment of the functional impact of the impairment is unnecessary because benefits clearly should be paid.

If an adult fails to establish that his impairment is medically equivalent to one of the Part A listed (conclusively disabling) impairments, the adult is allowed to proceed to a fourth step where the Secretary evaluates the claimant's residual functional capacity to determine whether the impairment prevents the claimant from doing work he has performed in the past. 20 C.F.R. § 416.920(e). If the claimant cannot perform his past relevant work, he proceeds to the fifth and final step where the Secretary evaluates whether, considering the claimant's residual functional capacity, age, education and past work experience, he can perform other work in the national economy. 20 C.F.R. § 416.920(f). See generally *Bowen v. Yuckert*, 482 U.S. at 141.

In contrast, the Secretary restricts a child to showing that his impairment strictly meets or equals the exact medical criteria in a listed impairment. Like the Part A listings for adults, the Part B listings reflect commonly occurring impairments in children that are of such severity that the Secretary has determined that *no* individual evaluation of the impairment's impact on the child is necessary (other than to the limited extent that some of the listings refer to functional impact) in order to presume conclusively that the child is disabled. 20 C.F.R. pt. 404, subpt. P, App. 1 (1986) (both Part A and Part B listings are contained in the same appendix). Thus, a child can be found to be disabled only if he meets or equals the strict medical factors of a *conclusively disabling* impairment. Under the Secretary's present policy for children, no amount of actual functional restriction, however severe, can be considered outside of the exact medical criteria in a listed impairment. See Social Security Ruling 83-19 (J.A. 243) and *infra*, 25-26.

The result of these different regulatory schemes is that a child will be conclusively denied benefits with-

out any recourse to an individualized showing when an adult with an *identical* impairment of *identical* severity with *identical* effects on function in a relevant sphere is entitled to make a showing that could permit him to receive benefits. See, *e.g.*, depositions of Dr. Bertram Kushner, a disability reviewing physician (J.A. 74-75) and Dr. Jerome Shapiro, SSA medical consultant (J.A. 85-87).

Congress did not set out specific functions that children perform that could be compared directly to the ability to work for adults. Nevertheless, it is reasonable to infer from the congressional emphasis on the functional impact of physical or mental impairments on adults that Congress intended disabling determinations concerning children to be similarly concerned with the impact of the impairment on the individual child's ability to function in a relevant sphere. Such an interpretation also gives the most natural reading to the phrase "comparable severity."

By using the phrase "comparable severity" it is reasonable to infer that Congress was not insisting that the Secretary utilize absolutely identical procedures or criteria for children as for adults. However, the use of this phrase in conjunction with a functionally focused statutory definition of disability for adults in fact underscores Congress's concern that disability determinations for *both* children and adults reflect the functional impact of impairments. Any impairment that is "medically determinable" as further specified in 42 U.S.C. § 1382c(a)(3)(C) and that results in the requisite limitation on the individual's ability to function within age-appropriate expectations should render the individual eligible for benefits.

The Secretary's interpretation of the phrase "medically determinable" is not persuasive. The Secretary draws a distinction between permissible "medical factors," which he appears to believe are embodied solely in the present listings, and all other evidence, referred to as "amorphous . . . unspecified non-medical factors," which he argues are

wholly outside of the intended statutory scheme. Pet. Br. 15. However, the statute requires only that an *impairment* be "demonstrable by medically acceptable clinical and laboratory diagnostic techniques." 42 U.S.C. § 1382c(a)(3)(C). As discussed above, medically acceptable clinical findings, especially in the area of pediatric disability, must be interpreted in light of the functional impact of a physical or mental impairment and are of sufficient variety to defy complete description in any listing. See *supra*, 3-6. Thus the statute's reference to "medically acceptable" techniques for determining impairments cannot fairly be read to exclude consideration of functional elements.*

B. The Legislative History Supports The Statute's Plain Language.

The legislative history accompanying Title XVI supports the view that Congress was concerned with the functional impact of physical and mental impairments on children. The House report accompanying the newly created Title XVI expressed Congress's concern that "disabled children who live in low-income households are certainly among the most disadvantaged of all Americans and . . . are deserving of special assistance in order to help them become self-supporting members of our society." S. Rep. No. 1230, 92d Cong., 2d Sess., *reprinted* in 1972 U.S. Code Cong. & Admin. News 5132-5133. Congress recognized explicitly that without financial assistance, such disabled children might never acquire the schooling and other skills necessary to function in the workforce as adults. *Id.* at 5138.

Congress again indicated expressly its understanding that Title XVI was intended to consider the functional impact of physical and mental impairments afflicting

* The Secretary's argument is further undermined by his own present regulations which, in the case of adults, note that residual functional capacity is a "medical assessment," that necessarily is concerned with the functional impact of physical and mental impairments. 20 C.F.R. § 416.945(a).

children when, in 1976, Congress specifically directed SSA to promulgate long-promised additional criteria and definitions for disability determinations of children under the age of 18. Furthermore, sponsors of the 1976 SSI disability amendments underscored Congress's primary concern with helping those low-income children with disabilities that threaten to render them disabled as adults. Senator Hathaway, a co-sponsor of the 1976 legislation, stated:

This test of comparable severity for a child's disability is required in current law. Like the test for determining the disability of an adult, a disability is not determined solely on medical grounds but also includes an evaluation of the impact of the disability on the person's abilities. In the case of an adult, that impact is looked at in light of his ability to engage in substantial gainful activity; the child's disability is to be looked at in terms of the comparable severity of its impact. Vocational ability, however, is clearly not a relevant test for determining the impact of a disability on a child. The assessment, rather, should refer to the impact of the child's handicap on his ability to function successfully within age-appropriate expectations. The child's functional capacity within the area of learning, language, self-help skills, mobility and social skills are decidedly more meaningful in determining both the severity of the impairment and the development potential of the child.

122 Cong. Rec. S. 34,026 (1976). In addition, Senator Hathaway recognized that the Secretary should consider broadly all relevant information concerning the individual child's condition. Thus, the Senator explained:

Medical criteria used in the broad sense of the total health development of the child could indeed provide the basis for determining the comparable severity of a child's disability. Medical criteria which are restrictively drawn . . . are not going to provide a definition of disability relevant to the person under the age of 18. A test of comparable severity is needed and is required in the present definition of disability

for such persons; but it should be based on tests relevant to a child, to his social and educational development

Id. See also 122 Cong. Rec. H. 27,855 (1976) (remarks of Rep. Mikva) and 122 Cong. Rec. S. 33,301-02 (1976) (remarks of Sen. Bentsen). Although such subsequent legislative history may be considered less dispositive of congressional intent than contemporaneous legislative history, see, e.g., *CPSC v. GTE Sylvania, Inc.*, 447 U.S. 102, 118 n.13 (1980), the later legislative history's declaration of an earlier statute's intent is entitled to "great weight" when that later declaration is based on an administrative construction that is consistent with it. *Red Lion Broadcasting Co. v. FCC.* 395 U.S. 367, 380-81 (1969). The Secretary had established a construction of the statute prior to 1976 that did require individualized assessments of each child's functional limitations. See *infra*, 19-20. Thus, the legislative history in 1976 is probative of Congress's intent to require individualized consideration of functional elements.

C. Congress Never Acquiesced In The Secretary's Current Interpretation.

The Secretary argues that his present interpretation of "comparable severity" is entitled to substantial deference because Congress was aware of and supported that interpretation at the time it enacted amendments to Title XVI in 1976 as part of the Unemployment Compensation Amendments of 1976, Pub. L. No. 94-566, § 501, 90 Stat. 2667. Pet. Br. 30-35. However, Congress has not ratified the Secretary's current interpretation because it was not aware of, could not have been aware of and would not have agreed to that interpretation when it acted in 1976. Indeed, the Secretary's present interpretation was not even formulated until significantly *after* the 1976 amendments.

As of 1976 the Secretary had maintained a consistent interpretation of the statute which *did* permit individualized determinations based on medical assessments of the functional impact of physical and mental impairments.

See *infra*, 19-20. Not only was that interpretation presented to the Congress, but the statements of the members most actively involved in the legislation indicate support for that interpretation. See *supra*, 16-17. Senator Hathaway, who served on the Conference Committee and whose amendment calling for the development of more explicit criteria for pediatric disability determinations was ultimately adopted, noted that the statutory test of comparable severity requires consideration of "the impact of the child's handicap on his ability to function successfully within age appropriate expectations. . . ." 122 Cong. Rec. S. 34,026 (1976). Similarly, there is nothing in the legislative history accompanying the 1976 amendments indicating any awareness of or support for a strictly limited "meets or equals a listed impairment" interpretation of comparable severity. The Senate report accompanying the amendments focuses solely on Congress's dissatisfaction with the lack of specific guidance from SSA and the resulting disparities in how similarly afflicted children in different states were being treated under the statute. There is simply no support for the Secretary's contention that Congress was aware of, much less acquiesced in, the Secretary's current restrictive policy.

In sum, the Secretary's belated (and inconsistent) attempt to cabin the meaning of "any medically determinable physical or mental impairment of comparable severity" in a way that excludes the impact of impairments on a child's functioning is contrary to the statutory language, Congress's intent in 1972 and Congress's assumptions in 1976 about the agency's own prior interpretation of that language.

II. THE SECRETARY'S PRESENT INTERPRETATION IS NOT ENTITLED TO DEFERENCE.

This Court has looked to a number of specific factors when determining whether a particular regulation properly carries out Congress's intent, including whether the regulation was a contemporaneous construction of the

statute; if the regulation was promulgated at a later date, how it evolved; the length of time the regulations have been in effect; the reliance placed on the regulations; the consistency of the agency's interpretation and the extent of Congressional scrutiny during any subsequent reenactments of the statute. *National Muffler Dealers Ass'n v. United States*, 440 U.S. 472, 477 (1979). An evaluation of these factors as they apply to the regulations implemented by the Secretary governing disability determinations for children under 42 U.S.C. § 1382c, even according the agency the most deferential standard of review, compels the conclusion that the regulations violate Congressional intent and are arbitrary and capricious.

A. The Secretary's Interpretation Is Not Longstanding.

In the years immediately following the passage of Title XVI, the Secretary, contrary to the position now stated in his brief, Pet. Br. 38-41, consistently interpreted "comparable severity" to encompass individualized determinations of the functional impact of impairments on children. In both 1973 and 1974, the Secretary issued Disability Insurance Letters to guide agency employees in the evaluation of childhood disability under the newly enacted SSI program.⁹ These earliest interpretations reflect a clear understanding by the Secretary of Congress's concern with the functional impact of impairments. Writing in 1973, the Secretary declared that "disability in children must be defined in terms of the primary activity in which they engage, namely growth and development, the process of maturation." J.A. 90. Therefore, the Secretary concluded that "comparable severity" should be applied to mean that "the severity of the impact of the child's impairment(s) must be 'comparable'

⁹ The Disability Insurance Letters ("DILs"), circulated by the SSA for internal use, represented the SSA's primary directives to state agencies on standard policies and operating procedures for making child disability determinations. Pet. Br. 36. Moreover, the DILs relevant to this case contain the Secretary's earliest statements interpreting the meaning of the statutory language relating to disability determinations for children. *Id.* at 36, 38.

to the severity of the impact of an impairment(s) which would prevent an adult from engaging in any substantial gainful activity." *Id.* at 91. (emphasis in the original).

The next year, in a supplement to the 1973 Disability Insurance Letter No. III-11, the Secretary referred to an impairment which interferes with a child's maturation as the equivalent of an impairment which prevents an adult from engaging in substantial gainful activity. *Id.* at 96. The Secretary specifically noted that the process of maturation involves:

(1) growth—increase in size and maturation of physical and functional characteristics, (2) learning, (3) mastering basic skills, and (4) emotional and social development . . . [t]he factors to be compared are the impact of the child's impairment on the child's life . . .

Id. (emphasis in the original). Moreover, the Secretary alerted those evaluating claims of childhood disability to consider learning and behavioral problems that lead to developmental delay. *Id.* at 96-97. In sum, the Secretary's present interpretation of the statute to preclude individualized consideration of the functional impact of impairments cannot be considered longstanding because it is at odds with the Secretary's contemporaneous interpretation of Title XVI.

B. Consideration Of Functional Impact Is Feasible.

The Secretary's present contention (Pet. Br. 44) that a functional benchmark is not feasible is belied by two facts. First, well-established medical practice *does* use functional benchmarks in evaluating disability in children. See *supra*, 3-6. Second, at the outset of the program the Secretary's policy directives articulated an understanding that Congress intended the statute to require pediatric disability determinations to reflect the functional impact on the individual child of his physical or mental impairment. This seriously undermines the Secretary's present contention that consideration of the functional impact of disability on children is somehow

infeasible or inappropriate.¹⁰ It is true that for children there is no single benchmark for conducting a functional analysis like employment for adults, but there are a number of readily identifiable criteria for evaluating functional performance in children of different ages. Certainly for most children age six to seventeen, school related functions would be a relatively simple standard to apply in an individualized determination. Moreover, the Secretary's artificial process of deciding whether to cubby-hole one medical impairment into a listed category is not inherently simpler or more efficient for the Secretary than making an individualized functional assessment, which physicians and other health professionals must do for each child anyway.

C. Exclusion Of Individualized Functional Assessment Is Contrary To Sound Medical Practice.

There is no basis in sound medical practice for the Secretary's suggestion that childhood disability can properly be determined based solely on "medical" factors that do not include functional considerations beyond those the Secretary has chosen to incorporate in a given Part B listing. Pet. Br. 38, paraphrasing DIL No. III-11 (J.A. 91). Because of the central role that development plays in the medical evaluation and treatment of children, comprehensive functional assessments are an integral part of a physician's evaluation of every child. In fact, it is not only feasible to include functional considerations in making a medical

¹⁰ The Secretary's recently released Notice of Proposed Rulemaking ("NPRM") establishing new listings for pediatric mental impairments underscores the feasibility, importance and propriety of functional factors in making a "medical" assessment of disability under Title XVI. See generally 54 Fed. Reg. 33,238 (Aug. 14, 1989). For example, the Secretary states that "[i]n childhood cases, as with adults, severity is measured according to the functional limitations imposed by the medically determinable mental impairment." 54 Fed. Reg. 33,238, 33,241 (1989) (to be codified at 20 C.F.R. pt. 404, subpt. P, App. 1, pt. B, 112.00C) (proposed Aug. 14, 1989).

assessment of a child's disability; it is absolutely essential. See *infra* 3-6.

1. *The Secretary's listings are inherently incomplete and often outdated.* The Secretary argues that any obligation to incorporate a functional analysis of a child's impairment into the standard used for determining childhood disabilities under § 1382c is met by the Part B listings that apply specifically to children. Pet. Br. 38-42. However, as even the Secretary has admitted, the listings (whether for children or adults) are not comprehensive, but include only those impairments that are more "commonly occurring" (44 Fed. Reg. 18,170, 18,175 (Mar 27, 1979) or "frequently diagnosed" 50 Fed. Reg. 50,068, 50,069 (Dec. 6, 1985). See also 43 Fed. Reg. 14,705, 14,706 (Mar. 14, 1977) (Secretary acknowledges that the children's listings "evaluate the more common impairments" and that children can "have an impairment that is not included in the Appendix.")

What makes the Secretary's slavish reliance upon the listing especially arbitrary is the fact that children manifest a significantly broader range of disabling diseases and conditions than do adults and yet adults are permitted to prove disability beyond the bounds of the listings. It is plainly unreasonable to restrict the universe of disabling conditions to a set of only 57 disorders, especially when those listings are extremely dated. Thus, the current listings exclude such well-known disorders as AIDS, Down syndrome, muscular dystrophy, infant drug dependency and fetal alcohol syndrome. For example, *amicus* National Organization for Rare Disorders has documented over 5,000 diseases and conditions, many of which can be severely disabling, but very few of which are listed in either Part A or Part B of the Appendix.

Even listings of relatively common impairments are totally out of step with current treatment practices. For example, the listing of bronchial asthma still contains a reference to parenteral (injected) medication as a measure of disability. Listing No. 103.03 (J.A. 213). In

fact, this therapy has long been supplanted by oral and inhaled medications for control of pediatric asthma of comparable severity. See generally Schwartz, *Children with Chronic Asthma: Care by the Generalist and Specialist*, 31 *Pediatric Clinics of North America* 87, 99-103 (1984). Similar deficiencies exist in the listings for hearing and vision impairments, where the Secretary's listings specify medical criteria that are inapplicable to infants and very small children. See Listings Nos. 102.02 and 102.08.¹¹

However, physicians long ago developed measures of hearing and vision disability that are widely used with very young children.¹² Despite their accuracy and widespread acceptance in the field, these up-to-date measures and diagnostic modalities will not result in findings of disability under the Secretary's archaic system. Because, unlike adults, children do not have recourse to any evalua-

¹¹ The listing for visual impairment calls for a finding of disability in children under three in only three circumstances: absence of accommodative reflex (which the listing specifically states will not be applied to children under six months), retrolental fibroplasia with macular scarring or neovascularizations (a fibrous growth behind the lens of the eye with a dense, visible scar or with development of new blood vessels), or bilateral cataracts with certain complications. Listing 102.02. The listing for hearing impairment for children under five calls for a finding of disability only for inability to hear air conduction thresholds at an average of 40 decibels or greater in the better ear. Listing 102.08.

¹² Vision can be estimated by observing the response to familiar objects (such as balls) of various sizes, and recording the distance at which the response is elicited. *Nelson's Textbook on Pediatrics* 1447 (Nelson, Behrman & Vaughan eds., 13th ed. 1987). Other widely used measures include optokinetic nystagmus (response to a series of moving targets) and visual evoked response (VER) testing (an electrophysiologic method of evaluating the response to light and special visual stimuli). *Id.* at 1448. Hearing loss in young children can now be measured through observation of behavioral response to noisemakers, auditory brain stem evoked responses (ABER) (computer-generated average of the brain's electrical response latency to auditory stimuli), or automatized infant hearing screening devices. *Id.* at 96-97.

tion outside of the listings (or strict comparisons to the listings), the inherent limitations of the Secretary's approach are more likely to result in inappropriate denials of benefits for children than for adults.

2. *The medical equivalence regulation is overly restrictive.* The Secretary relies heavily on the existence of his "medical equivalence" regulation to salvage the regulatory scheme for children. Pet. Br. 40, 42. However, the regulation, adopted in 1980 (45 Fed. Reg. 55,566, 55,570-71 (Aug. 20, 1980)) fails to provide sufficient latitude to permit individual children to show that their impairments are of "comparable severity" to an impairment which an adult could demonstrate entitled him to a determination of disability.

According to the regulation, a child whose medical findings (symptoms, signs and laboratory findings) do not meet the medical findings of one of the impairments listed in Part B or, if there is no separate listing under Part B, in Part A, can only be found to be disabled if he shows that his impairment is "medically equivalent" to a listed impairment. 20 C.F.R. § 416.926(a). The regulation also states that an impairment is disabling if the Secretary's physician (who need not be a specialist in pediatrics or in the specific impairment) determines that the medical findings of impairment are equal to the medical criteria of an impairment that the Secretary determines most closely matches that manifested by the child. *Id.*

The difficulty with this rather tautological definition is that by insisting on equality of severity with necessarily limited listings, the Secretary prevents a significant number of children from receiving an individualized determination that their impairment is of "comparable severity" to an adult impairment that would be found to be disabling. It is wholly arbitrary to require, for example, that a child with dystrophic epidermolysis bullosa (a rare, life-threatening, blistering disease that affects the skin and internal organs, and that usually leads to death

before the age of 30) demonstrate that his medical findings are "equal in severity" to a listing, such as Catastrophic Congenital Abnormalities or Diseases which applies only if the impairment is either incompatible with extrauterine life or expected to prevent a child from surviving and developing to the level of a two year old. Listing 110.08.¹³ The likelihood that any physician could make meaningful comparisons between extremely rare diseases and the set medical criteria listed by the Secretary means that children will be denied benefits for reasons wholly unrelated to the extent of their disability. This is neither administratively convenient nor rational.

This unrealistically restrictive definition of equivalence has been further limited by a subsequent HHS directive that explicitly *prohibits* a determination that an impairment is "equal" to a listed impairment based on an assessment of equivalent "overall functional impairment." Social Security Ruling ("SSR") 83-19 (J.A. 236).¹⁴ The Ruling further instructs SSA personnel that

[t]he level of severity in any particular listing section is depicted by the *given set* of findings and not by the degree of severity of any single medical finding—no matter to what extent that finding may exceed the listed value The functional consequences of the impairments (i.e. RFC) [Residual Functional Capacity], irrespective of their nature or extent, *cannot* justify a determination of equivalence.

Id. (emphasis in original). Thus, the regulations prohibit a determination of disability in cases where a medical assessment of equivalence is based in part on a de-

¹³ The Secretary has determined that this is the closest listing to epidermolysis bullosa. However, a child with E.B. will not "equal" the specific medical criteria in listing 110.08, despite the fact that the disease is significantly more disabling than many other listed impairments.

¹⁴ Social Security Rulings are statements of policy or interpretive rulings issued by the Secretary that are binding on all SSA adjudicative personnel. *Marcus v. Bowen*, 696 F. Supp. 364, 371 (N.D. Ill. 1988).

termination that *functionally* a child suffers from an impairment of equal severity to a listed impairment. Given the manifold variety of disabling conditions among children, such a strict interpretation of comparable severity ensures that many children who suffer from disabling impairments are unable to receive benefits, even though in any true medical sense their condition is equally disabling.

One compelling example shows why the Secretary's approach should be rejected. Monisha Smith is a ten-month-old infant with spina bifida myelomeningocele. Monisha's disease has resulted in substantial developmental delays, although currently she does not meet the 50% developmental delay criterion as set forth in the Secretary's regulations. Listing 112.05A. Her legs have been affected by some paralysis, so she is unable to crawl. Although all infants are incontinent, Monisha's disease requires that she be catheterized every two hours, and that her bowel be manually vacuated.¹⁵ Unlike other children, who by age two or three gain voluntary bowel and bladder control, Monisha will never gain such voluntary control. Her impairments, although severe and ongoing, do not satisfy the Secretary's current listed standards.¹⁶ Eventually, Monisha's impairments will result in her qualifying for disability benefits, not necessarily because her condition

¹⁵ See Sugar, *The Neurogenic Bladder in the Child with Myelomeningocele: Neurophysiology and Treatment Using Intermittent Catheterization*, in *Spina Bifida: A Multidisciplinary Approach* 70, 72-73 (R. McLaurin, et al., eds. 1986) and Whitehead, *Bowel Management in Children with Spina Bifida*, in *Spina Bifida: A Multidisciplinary Approach* 323, 329-30 (R. McLaurin, et al. eds. 1986).

¹⁶ She does not satisfy the criteria under listing 110.08 because spina bifida is compatible with life outside the womb and she will eventually be able to function above the level of a two-year old. She likewise fails the criteria under listings 111.06 and 111.08 because, at her age, the paralysis cannot be said to have interfered yet with "age appropriate major daily activities," although it significantly interferes with fine and gross motor development and will interfere with walking.

has deteriorated but rather because her *unchanged* level of impairment will be judged as meeting the listings.

Infants with spina bifida are not unique in being unable to demonstrate "medical equivalence" to one of the listed impairments. Some children are denied benefits because their particular clinical symptoms are so different from those in the listing that a finding of equivalence is highly unlikely, although as adults they would readily be able to show severe functional impairment.¹⁷

The Secretary's response to this fundamental criticism is twofold. First, he argues that "comparable severity" does not require identical treatment between children and adults. Pet. Br. 16, 24-25. Certainly, "comparable severity" does not on its face or in context require that children and adults be treated identically under the program. *Amici* agree with the Secretary's early understanding of the important differences that *should* be taken into account when assessing disability in children. A given impairment that disables a child from growing, developing and maturing might not disable an adult from engaging in substantial gainful employment. However, appropriate recognition of and allowance for the different manifestations of disabling impairments between adults and children does not in any way justify the Secretary's present regulatory scheme which prohibits

¹⁷ For example, the Part B listing contains one entry for esophageal impairment, restricted to conditions that involve narrowing of the esophagus and result in malnutrition (itself defined as 15 percent loss in weight or weight below the third percentile on standard growth charts). Listing 105.03 (J.A. 219). The listing fails to make any provision for additional esophageal disorders that afflict children, such as achalasia (failure of the muscles responsible for swallowing and peristalsis, see Berquist, et al., *Achalasia: Diagnosis, Management, and Clinical Course in 16 Children*, 71 *Pediatrics* 798 (1983)), and gastroesophageal reflux (muscle failure permitting gastric contents into the esophagus, with resulting damage to the esophagus and related pulmonary symptoms, including aspiration pneumonia, Jolley, et al., *Surgery in Children with Gastroesophageal Reflux and Respiratory Symptoms*, 96 *J. Pediatrics* 194 (1980)), although those disorders are equally disabling.

medical evaluations of comparable severity that are based on functional equivalence, unless the child's medical findings are strictly equal to the specific set of medical findings in a listed impairment. As previously discussed, this regulatory scheme results in grossly unequal treatment of children which is manifestly inconsistent with any plausible reading of the statutory term "comparable."

The Secretary's second response is that some imperfection in the system is not evidence of a systematic problem with the methodology the agency has chosen to implement Congress's directives. Pet. Br. 42. As to this point, the shortcomings of the present regulatory scheme for disability determinations of children involve more than a few outdated listings or a handful of excluded rare diseases. The imperfection in the scheme is systemic. By providing for additional steps for adults outside of the requirement that a claimant's impairment meets or equals a listed impairment, the Secretary has always silently acknowledged that a limitation of meeting or equaling a listed impairment, however complete a listing the agency was able to devise, would not satisfy Congress's directive to provide benefits to those who suffer from "any" impairment that prevents them from engaging in any substantial gainful activity. In light of this recognition of the inherent limitations in the listings applied to adults, it is difficult to comprehend how a slightly more expanded listing which a child must "meet or equal" can satisfy Congress's directive that children with impairments of "comparable severity" be found disabled, particularly when medical professionals know that children are much more likely to suffer from unusual disabling diseases and conditions than adults.

This latter point underscores another obvious flaw in the Secretary's argument about "comparable severity," namely that the term "comparable" on its face does not support a methodology that systematically underprotects children compared to adults. Ordinarily, "comparable" indicates that on occasion a child with a less severe medi-

cal condition than an adult nevertheless would receive disability benefits. But the Secretary's methodology requires all error to be on the side of denying benefits to children. Given the special needs of children, this approach is wholly irrational and should be rejected by this Court.

* * *

Amici do not underestimate the difficulty of administering a vast program such as Title XVI and they recognize the Secretary's need for establishing a solid base of objective criteria to permit uniformity in treatment of similarly afflicted individuals. Nevertheless, ease of administration cannot justify a regulatory system that in design and practice serves systematically to exclude from receiving benefits a substantial number of disabled children from low-income households on the sole basis that the technical medical findings of their physical or mental impairment fail to fit neatly into a limited number of boxes of specified signs, symptoms and findings. The medical profession does not treat patients as items in categories based strictly on diagnostic tests and symptoms and neither should the Secretary in deciding whether any medically determinable impairment is comparable to another. Instead, medicine considers functional ability in deciding what treatment to pursue and so should the Secretary of HHS in deciding whether benefits should be awarded. Despite the deference that is normally accorded an agency's interpretation of a statute which it administers, the present regulatory scheme for determining disability benefits for children under Title XVI is so clearly contrary to the statutory directive, the congressional intent and good medical practice that it cannot stand.

CONCLUSION

For the foregoing reasons, the judgment of the court of appeals should be affirmed.

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